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Identifying and Defining the Structures  
That Guide the Implementation of  
Participant Direction Programs and  
Support Program Participants: A  
Document Analysis

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### ABSTRACT

Participant direction (PD) programs offer the individual with a disability or his/her surrogate decision maker varying degrees of choice and control over the individual's supports and services. We conducted a document analysis using grounded theory methods to identify the design elements of participant direction programs in long-term care. We analyzed 53 documents across multiple disabilities and funding sources. We identified and defined two major components of PD programs: policy and aid and assistance. The component of policy was represented by three structures that guide implementation of participant direction programs: (a) option to participant direct, (b) participation stipulations, and (c) provider qualifications. The component of aid and assistance was represented by 11 structures that support program participants: (a) financial management services, (b) employer of record, (c) emergency back-up, (d) worker registry, (e) advice/counseling, (f) managerial assistance, (g) information dissemination products, (h) service quality monitoring, (i) service coordination, (j) participant training, and (k) provider training. Each structure was represented by one or more continua depicting the range of choice and control participants may have over the structure. The findings of this study have implications for improving the standardization of research on participant direction programs and the development of long-term care policy.

*Keywords:* consumer direction, participant direction, self-direction, disability, long-term care

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### Identifying and Defining the Structures that Guide the Implementation of Participant Direction

#### Programs and Support Program Participants: A Document Analysis

The need for long-term care supports and services is growing (Kaye, Harrington, & LaPlante, 2010). Long-term care refers to the supports and services needed to meet individual care and assistance needs over an extended or ongoing period of time for those who are unable to be fully independent. Traditionally, publicly paid long-term care has been provided through an agency direction model in which the individual with a disability has minimal input regarding the decisions made and the services provided to meet his or her needs (Clark, Hagglund, & Sherman, 2008; Jamison Rissi, 2007; O’Keeffe, Wiener, & Greene, 2005). In agency direction, the agency typically draws down the money from the benefit source (e.g., Medicaid); service providers are employed by the agency, and the individual is a recipient of the agency’s services. The agency typically is the employer of the service providers and assumes the responsibilities of recruiting, hiring, training, scheduling, managing, disciplining, and paying the service providers.

By contrast, programs of participant direction offer the individual or his/her surrogate decision maker (hereafter collectively referred to as “participants”) varying degrees of decision-making authority. Decisions may include deciding what goods and services are purchased, how and where they are implemented, and by whom. Programs are premised on the belief that participants should be primarily responsible for directing their supports and services, regardless of disability or extent of support needs (National Institute of Consumer-Directed Care Services, 1996). However, the distinction between agency direction and participant direction programs is not black and white; rather, it is characterized by shades of gray.

#### **Variation in Programs of Participant Direction**

In 2001, Doty and Flanagan (2002) estimated that there were 486,000 participants directing supports and services in 139 different home and community-based programs in 49

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states. These programs ranged in size from fewer than 100 participants to more than 5,000 participants. Since 2001, federal legislation (e.g., New Freedom Initiative of 2001 and Deficit Reduction Act of 2005; Claypool & O'Malley, 2008; Jamison Rissi, 2007) and an expansion of grant-funded demonstration projects (e.g., Systems Change Grants and Cash and Counseling; Tritz, 2005) have increased the availability and variability of participant direction programs across the country. These programs transcend disability categories (e.g., intellectual and/or developmental, traumatic brain injury, physical, elderly) and funding sources (e.g., state Medicaid plans, Medicaid waivers, Medicare, Department of Veterans Affairs Housebound and Aid and Attendance Program, National Family Caregivers Support Program, state funds; Infeld, 2005; Jamison Rissi, 2007; Nadash & Crisp, 2005; O'Keeffe et al., 2005; Tritz, 2005).

Each funding source has its own rules and regulations regarding the expenditure of the funds and degree of participant choice and control permitted (O'Keeffe et al., 2005; Tritz, 2005). No two programs are identical in their design; each offers differing levels of choice and control and support to participants. As such, there is a "continuing lack of clarity of what is meant by [participant] direction" (Infeld, 2005, p. 14), and this variability in design has left little opportunity for rigorous research regarding participant outcomes (Nadash & Crisp, 2005; National Council on Disability, 2004).

### **State of Existing Research**

A number of studies on participant direction, using both qualitative and quantitative methods (Beatty, Richmond, Tepper, & DeJong, 1998; Benjamin & Matthias, 2000; Caldwell, 2006; Caldwell & Heller, 2003; Caldwell & Heller, 2007; Clark et al., 2008; Doty, Benjamin, Matthias, & Franke, 1999; Foster, Brown, Phillips, Schore, & Carlson, 2003; Foster, Brown, Phillips, & Carlson, 2005; Heller, Miller, & Hsieh, 1999), have focused on topics specific to individual or family caregiver outcomes, including: (a) satisfaction with services, (b) existence of

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unmet needs, (c) physical well-being (e.g., health and safety), (d) emotional well-being, (f) financial well-being, (g) community integration, (h) general quality of life, (i) satisfaction with life, and (j) empowerment. Individuals with disabilities in the participant direction programs studied experienced better outcomes in these areas than their agency direction peers.

Other areas of study concern aspects of program functioning (Benjamin & Matthias, 2004; Dale, Brown, & Phillips, 2004; Dale, Brown, Phillips, & Carlson, 2003a; Dale, Brown, Phillips, Schore, & Carlson, 2003b; Doty et al., 1999; Foster et al., 2003; Meng et al., 2006), such as (a) costs of operation, (b) service availability and accessibility, and (c) service provider working conditions, quality, characteristics, and satisfaction. The research on program functioning compares individuals, surrogates, or service providers in participant direction programs to those in, or on waiting lists for, comparable agency direction programs.

### **Gaps in the Existing Research**

However, research has not yet identified the many different organizational structures of participant direction, nor the multitude of system supports made available through them. Some researchers have cross-analyzed multiple programs of participant direction, comparing and contrasting them (Doty, Kasper, & Litvak, 1996; Doty & Flanagan, 2002; Infeld, 2005). Kendrick and colleagues (2006) in a review of programs developed by Real Choice Systems grantees defined participant direction, identified the six levels of participant choice and control, described the common elements over which a participant could have authority, and provided examples of support or assistance that may be available to assist participants in directing their supports and services. Though no research has looked across multiple disabilities and funding sources to address the issue of variability in program design.

The field of participant direction lacks consistent definitions of terms and has not adequately defined or explained the variables of study (National Council on Disability, 2004).

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Additionally, the issue of program variability, or which program structures lead to the best outcomes for program participants, has yet to be studied. If we identified the structures that are typically a part of participant direction programs, researchers could conduct cross-program research, determine which structures are associated with specific participant outcomes, and provide evidence to support the design of participant direction programs.

### **Study Purpose and Research Question**

The results presented in this manuscript represent a portion of the findings from a larger study conducted for the purpose of analyzing the design of participant direction programs across disability types and funding sources. In this article, we specifically address the findings that answered the question: What structures are in place to guide the implementation of participant direction programs and support participants in directing their long-term care?

### **Methods**

Qualitative methods were best suited to the research question due to the diversity of programs and exploratory nature of the question. Since programs of participant direction exist in every state in the U.S. (Breihan, 2007; Claypool & O'Malley, 2008; Doty & Flanagan, 2002), many of which were documented in the literature, we determined that an analysis of recent literature was the most efficient and effective way to gather a broad array of data on program designs across multiple states. We conducted a document analysis using grounded theory data analysis methods, which consisted of a systematic examination of the document sample using constant comparative analysis.

### **Data Collection**

**Source identification.** We determined the four document sources through a preliminary search using three terms associated with participant direction research and practice: self-determination, self-direction, and consumer direction. We did not use the term *participant*

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*direction* in the preliminary searches because it was rarely used in the literature from 2004-2008. However, we use *participant direction* throughout this paper in lieu of other commonly used terms due to the recent establishment of the National Resource Center for Participant-Directed Services at Boston College (<http://www.bc.edu/schools/gssw/nrcpds/>).

We reviewed the preliminary search results from each potential data source for quantity (i.e., how many results were returned) and diversity (i.e., type of document, disability categories and programs represented). We searched 12 social science library databases for peer-reviewed literature, a scholarly research focused search engine and a clearinghouse for gray literature (i.e., documents not published commercially, such as program manuals, organization reports, position statements, policy briefs). We selected the sources for gray literature to search based on site descriptions and previous research (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012). We confirmed their selection by verifying their viability as data sources in the preliminary search of each source's content. Using the search results, we identified four sources for documentary data on participant direction: (a) Proquest Research Library (library database), (b) Academic Search Premier (library database), (c) Google Scholar (search engine), and (d) The Clearinghouse for the Community Living Exchange Collaborative (clearinghouse).

**Sample selection.** We searched the four data sources using an expanded search term list which included the following eight terms and other derivations of these terms: (a) consumer control, (b) consumer direction, (c) individual budgeting, (d) individualized funding, (e) participant direction, (f) person-directed, (g) self-determination, and (h) self-direction. First, we searched the library databases, focusing on peer-reviewed literature, documenting total returns and results retained for the initial sample. Then we searched the sources for gray literature.

Our data searches using the search engine, Google Scholar, returned over 44,000 combined results associated with the terms self-determination, self-direction, and self-directed.



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Calculations from the library databases' search results yielded that less than 1% of all results returned on these three terms met our inclusionary criteria. As such, we did not review the Google Scholar results from searching those three terms. We did review a total of 9,910 documents, screening them by title and, if needed and available, a cursory review of the abstract or introduction. We selected the document sample through application of a two-stage filtering process: (a) inclusionary criteria and (b) exclusionary criteria.

*Inclusionary criteria.* We identified an initial document sample using three inclusionary criteria. The first criterion was a restricted publishing timeframe, including only 2004 to 2008 (document analysis occurred in 2009-2010). We used this criterion to ensure that the identified documents represented current policy, practice, and data from various programs of participant direction. Second, content of the documents must have information relevant to the service model of participant direction. We achieved this by assuring that all documents had at least one of the expanded search terms, or its derivation, in the (a) title, (b) keywords/topics/subjects, (c) abstract/summary, or (d) table of contents of the document and by reviewing the abstract/summary of the document for content relevant to service model of participant direction. Finally, we restricted the sample to documents addressing participant direction programs in the U.S. only. We compiled the documents meeting the inclusionary criteria in a reference table. Applying the inclusionary criterion to the 9,910 documents was an iterative process, resulting in an initial sample of approximately 550 documents.

*Exclusionary criteria.* Once we had identified the initial sample, we reviewed the documents for additional details and identified the following for each document and added the data to the existing table of references: (a) disability populations described (e.g., physical disability, intellectual and developmental disabilities), (b) name of the program(s) researched or described (e.g., California's In-Home Supportive Services Program), and (c) type of document

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(e.g., program manual, organization report, peer reviewed research article). We used this information to facilitate sorting the results and applying the exclusionary criteria.

We applied the following four exclusionary criteria to the initial sample. First, we excluded any documents that did not emphasize participant direction of long-term care supports and services as the focus of the document. Second, we excluded documents whose primary purpose was to review the research literature on participant direction, as we could not keep true to the date criteria nor gather sufficient data descriptive of the programs from such documents. We did, however, review their bibliographies to confirm that the search process was finding key documents in the field. Next, to ensure a range of implementation of participant direction and to prevent a disproportionate representation of one program, we used the third and fourth exclusionary criteria to reduce redundancy of authorship and program in the sample. Regarding authorship (third criterion), when the same author appeared as the first or second author on multiple documents, we selected the most recent document. Regarding redundancy of programs in the literature sample (fourth criterion), we selected one document per program of participant direction (e.g., if there were three articles on California's In-Home Supportive Services Program, we selected one of the three) based on relevancy of content to the study purpose and question. We did not apply the fourth criterion to documents that provided a broad overview of several programs (e.g., comparative reviews of programs). The application of the exclusionary criteria resulted in a final sample of 53 documents from multiple sources.

*Final sample.* The documents in the final sample referenced programs in every state as well as the District of Columbia and American Samoa and included multiple disabilities (frail elderly, intellectual and developmental disabilities, mental illness, other health impairments, physical disability, sensory disability, traumatic brain injury). In order to clearly categorize and understand the context of the documents in the sample (Merriam, 1998), we described each type

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of document, identifying the (a) kind of content it relayed, (b) role of the person or organization that created it, (c) purpose for its creation, and (d) source from which it could be retrieved.

### **Data Analysis**

Below we describe the qualitative document analysis process in three stages: (a) open coding, (b) conceptual categorization, and (c) axial coding.

**Open coding.** We purposefully selected 12 documents for this stage for one of the following reasons: (a) the document needed a closer look to see if it really belonged in the sample; (b) the document provided an extensive overview of participant direction and would be a source of rich data for the development of the codebook; or (c) the focus of the document (e.g., policy, budgeting) was not already represented in others selected for open coding.

We used open coding (Corbin & Strauss, 1990) on 12 of the 53 documents, coding line-by-line coding and using constant comparative methods (Glaser & Strauss, 1967). We looked for similarities and differences among the coded data (Corbin & Strauss, 1990) and organized the initial codebook in a table, which contained the (a) codes, (b) raw data from the documents representing that code, and (c) reference sources for the raw data.

The coding team met bi-weekly with peer debriefers to review the coding and discuss initial codebook development and emerging themes. The peer debriefers also provided check-coding (Miles & Huberman, 1994) for 42% of the documents used in this stage.

**Conceptual categorization.** As we compared the coded data of each new document to the existing data in the table, conceptual categories began to emerge. We used *in vivo* codes, terms specific to the organizational structure of participant direction programs and descriptive of their implementation (Charmaz, 2006). Grounded theory's constant comparative process facilitates close examination of the categorizations of the data, calling out errors and refining the concepts until a stable codebook and themes emerge (Corbin & Strauss, 1990).

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**Axial coding.** In axial coding, the previously identified categories and subcategories are tested against additional data, resulting in further development and refinement of the codebook (Corbin & Strauss, 1990). Through this process, relationships between categories and subcategories are further described, and their relationships to others emerge. In this stage, we recoded the initial 12 documents using the revised codebook. In doing so, we confirmed the conceptual categories and gathered additional data (Charmaz, 2006).

Next, we applied the revised codebook to the remaining 41 documents in the sample. To accomplish this, we developed a document analysis tool to facilitate analyzing large amounts of data (Altheide, 1987; Charmaz, 2006). In developing the tool, we defined each component and the structures associated with it, including specific examples of each from the data (Charmaz, 2006). Before applying it to the remaining sample, we tested it on 25% of the initial coding sample, to ensure it adequately captured known characteristics of the data. The tool facilitated identification of new categories as they emerged, analysis of new data in comparison with existing data, and assessment of its fit in the existing structure.

Using the document analysis tool, we engaged in paired coding of eight documents. During paired coding, two members of the research team independently coded the same document, and then met to review all codes and supporting raw data (i.e., quoted content). When meeting, we identified codes that needed clarification or amendment and refined the tool as needed. We worked to achieve a consensus on the meanings of different codes (Miles & Huberman, 1994, p. 64). We achieved 85% reliability for using the analysis tool on both the 7<sup>th</sup> and 8<sup>th</sup> documents used in paired coding and began independently coding the remaining sample. To ensure continued reliability and reduce coder drift throughout the axial coding, we engaged in paired coding of two of the documents in the remaining sample, and the principal investigator check-coded three of the documents independently coded by other team members.

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We reached saturation of conceptual categories while coding the 53-document sample. According to Glaser and Strauss (1967), saturation is achieved when “no additional data are being found whereby the [researcher] can develop properties of the category” (p.61). We determined that we had reached saturation when coding from the last eight documents in the sample did not result in new data requiring revisions or additions to the analysis tool.

### **Trustworthiness Measures**

We engaged in multiple measures to ensure trustworthiness in this study. First, the principal investigator recorded, in a dated journal, notes from meetings with peer debriefers and all decisions regarding study design and implementation (Charmaz, 2006). Second, we employed the assistance of peer-debriefers to review document coding, conceptual category development, and the emerging organization of the categories (Miles & Huberman, 1994). Third, we engaged in both paired coding and check-coding during the axial coding stage, ensuring more eyes on the data and greater trustworthiness. Finally, we triangulated the data in multiple ways by using multiple: (a) investigators, (b) data sources, and (c) types of documents developed for multiple purposes (Creswell, 2007; Maxwell, 2005; Merriam, 1998).

### **Limitations**

When using documents as a data source, there are certain limitations to consider. First, documents are a record of an observer’s (e.g., agency, researcher, individual) perceptions of participant direction. Therefore, the detail in description is reliant on the accuracy of the observer’s recollection and record of the information. Second, we analyzed documents that were created for various purposes and different audiences, making some more fruitful sources of program descriptions than others. Third, limitations existed regarding the type of document. We did not analyze books even though a book may have offered a more in-depth look at the organization and implementation of programs of participant direction. We also did not include

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websites, although it could be posited that the web pages within the website are virtual documents. There are several websites that are devoted to the implementation of participant direction supports and services. Finally, articles published since the gathering of the sample are not represented in this study and, due to their recent publication, would have offered an even more current understanding of participant direction.

### Findings

The purpose of this study was to determine what structures are in place to guide the implementation of programs and support participants in directing their long-term care. Using qualitative analysis of the documents, we identified two components, (a) policy and (b) aid and assistance, the structures and continua of choice and control associated with each (see Table 1).

<<insert Table 1>>

### Policy

Policy refers to any local, state, or national policies that influence a participant's ability to direct supports and services. Under policy, we identified three structures: (a) option to participant-direct, (b) participation stipulations, and (c) provider qualifications.

**Option to participant-direct.** There was a continuum associated with when and how the option of participant direction was made available to the participant. Some documents indicated that, "after meeting eligibility requirements," individuals were given "a choice about what kind of services to receive: facility or residential services, provider directed services in the home, or if available, consumer-directed services in the home" (DHHS of NC, 2005, CDS1-p.17). For some participants, however, the option to direct was more limited and became available to the participant only when he or she became "dissatisfied" (Kennedy, 2004, p. 229) with the traditional agency direction model. Other policies restricted participant direction to residents of certain catchment areas (CMS, 2008; Koyangi et al., 2008). Only one state, California, had

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policy making participant direction the default option for individuals receiving long-term care supports and services (Barnes et al., 2006; Claypool & O'Malley, 2008; Tritz, 2005).

**Participation stipulations.** There were two continua associated with eligibility for participant direction, one addressing the individual's capacity to participant-direct and the other addressing surrogate participation in directing the individual's supports and services.

The first continuum addressed an individual's capacity to participant direct. Many programs did not require a capacity test of the individual; an expression of interest in participant direction was all that was needed, regardless of need for a surrogate decision maker (Flanagan, 2005; Squillace & Firman, 2005). In these programs, "program administrators tend[ed] to think of the [participant] as a dyad consisting of both the individual and his or her family" (Jamison Rissi, 2007, p. 8). Although recognition of the dyad participant (individual and family) was common, a few programs required a physician's letter (Claypool & O'Malley, 2008) or a "nurse's medical assessment" (Bates, 2006, p. 4) indicating that the individual was capable or had a surrogate to act on his or her behalf. Other programs required that the individual pass a test, training course, and/or assessment or evaluation of the individual's capacity before allowing participation (Claypool & O'Malley, 2008; Flanagan, 2005; Griffin, 2005; Tritz, 2005).

The second continuum concerned whether an individual was permitted a surrogate to direct his or her budget and supports and services. Some programs required that the individual be able to independently handle all responsibilities (Griffin, 2005; Spillman et al., 2007). Other programs allowed an individual "with cognitive impairments ... to choose a representative to administer the [individualized budget] on his or her behalf" (Topeka Independent Living Resource Center Inc., 2005, p. 1). Still others expected the individual to be capable of directing his or her own care but allowed support with budgeting (O'Keeffe et al., 2005).

In addition to the foregoing continua, several documents also addressed characteristics of

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the individual and surrogate that could prohibit their participation. For example, if the individual required 24-hour care (Claypool & O'Malley, 2008), lived in congregate housing (e.g., nursing home, ICF/MR, or group home; Griffin, 2005), had an intellectual disability (Griffin, 2005), or had or needed a guardian or conservator (O'Keeffe et al., 2005), the individual was not allowed to participant direct. Other documents identified various criteria regarding who could act as a surrogate decision maker. For instance, in Minnesota, surrogates (a) may not be paid service providers, (b) must "be at least 18 years old," (c) must be available to both the individual and his or her service providers, and (d) must "monitor care at least once a week" (Minnesota Department of Human Services, 2004, p. 7). Some programs allowed the surrogate to also be a guardian or person with power-of-attorney for the individual (O'Keeffe et al., 2005), while other programs prohibited that relationship "to avoid conflict of interest" (McGaffigan, 2008, p. 14).

**Provider qualifications.** There were three continua concerning provider qualifications: (a) conducting background checks, (b) hiring family and friends, and (c) licensing requirements.

One commonly required qualification concerned conducting background checks, typically including criminal background and abuse registry screenings. This reflected two levels of participant choice: (a) participant could choose whether to conduct background checks, or (b) participant was required to conduct background checks. If required, this was typically dictated by state policy, regardless of the type of service model and was required for all service providers in the state ("Kansas," 2004). However, some programs allowed more discretion, recommending that the participant "seriously consider doing a criminal background check" (The ARC of Tennessee, 2004, p. 60), but left the decision up to the participant (Griffin, 2005).

Another provider qualification concerned who could be hired to provide services. The rules and regulations governing the funding source for the services generally dictated this. Some programs had no restrictions regarding who could be hired, allowing participants to "hire legally



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responsible individuals” (McGaffigan, 2008, p. 4), including a spouse or legally responsible parent. Other programs prohibited spouses and parents (Doty, 2004; Kim et al., 2006) but allowed other family members (e.g., daughter, grandson) to be paid service providers (Squillace & Firman, 2005). The most restrictive requirement prohibited hiring any family members, allowing only non-relatives (Flanagan, 2005; Kassner, 2006; Meng et al., 2006).

The last provider qualification concerned whether the service provider must be licensed, certified, approved, contracted, or enrolled (hereafter “licensed”) by a designated state agency (e.g., state Medicaid agency). This qualification was governed by the rules and regulations of the funding source for the services. In some programs, the service provider was legally employed by the participant and had no requirement for licensure with the state (Gage et al., 2005; The ARC of Tennessee, 2004). These programs allowed the participant to “choose virtually any provider ... whether a private nonprofit organization or for-profit corporation or an individual” (Breihan, 2007, p. 366). Others required that the service provider be under the supervision of or employed by a licensed service provider, allowing the participant to “find a [personal assistant] ... and then have that person hired by an agency” (The ARC of Tennessee, 2004, p. 2). Finally, some programs required that anyone providing services be licensed; therefore, service providers “in many consumer-directed programs are ‘independent providers’ and may be categorized as support service employees of the [participant]” (Scherzer et al., 2007, p. 30). Family and friends must meet state licensure requirements and become independent service providers to work for the individual. Other programs more restrictively required all licensed service providers to be an agency (e.g., a home health agency), necessitating the participant to “register as a personal care agency solely for the purpose of directing [the individual’s] care” (Griffin, 2008, p. 13).

### **Aid and Assistance**

Aid and assistance referred to the various types of support provided by the state or its

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agent that could be available or required to be used by participants directing their supports and services. Under the component of aid and assistance, we identified 11 structures: (a) financial management services, (b) employer of record, (c) emergency back-up, (d) worker registry, (e) advice/counseling, (f) managerial assistance, (g) information dissemination products, (h) service quality monitoring, (i) service coordination, (j) participant training, and (k) provider training. The continuum of choice and control in the aid and assistance component was succinct. Choice concerned whether the aid and assistance was available, and control concerned whether use of the aid and assistance was required. Whether a structure was present in a program of participant direction depended entirely on the design of the program (Claypool & O'Malley, 2008).

**Financial management services.** Financial management services were the most frequently available and required form of aid and assistance and consisted of providing support to participants “in handling the business aspects of being an employer” (Blue-Banning, 2007, p. 62) of service providers. Most programs, because of the policy requirements of the funding source, used a financial management service to ensure accountability for funds and employer payroll responsibilities, disallowing the participant to assume responsibility for the activity of payroll management (Cloutier et al., 2006; Infeld, 2005). In such programs, a fiscal intermediary may contract with the state or its agent to perform such functions as “tracking and monitoring budgets, performing payroll services, and handling billing and documentation” (Massachusetts Department of Mental Retardation, 2007, p. 10) for all participants in the program, making this form of aid and assistance both available and required. Other programs made financial management services available but allowed the participant to “choose how much help [they] need[ed] and with which aspect of [the] program” (The ARC of Tennessee, 2004, p. 97).

**Employer of record.** If the use of a financial management service was required, then it was also common for the agency assuming this role to act as the employer of record (Clark et al.,

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2008; Colorado Department of Health Care Policy and Financing, 2007; “Kansas,” 2004) and assume legal responsibility for hiring the service providers. Other programs “provide[d] supports to enable the participant to be the ‘employer of record’” (DHHS of NC, 2005, CDS1 -p. 51).

**Emergency back-up.** Emergency back-up services were required when a regular employee was absent. Depending on the responsibilities agreed upon by the participant and agency acting as the employer of record, the agency could “arrange for adequate backup,” or the participant could need to “arrange for their own backup” (Rosenberg et al., 2005, p. 15).

**Worker registry.** In some programs, the public authority in charge of the program “maintain[ed] a registry of providers who [were] interested in working for [participants]” directing their own supports and services (Barnes et al., 2006, p. 6). In other programs, a designated professional or agency could be “responsible for compiling a registry of potential direct care workers” (Claypool & O’Malley, 2008, p. 11), with little follow-up to ensure the list remained current (Surpin, 2007). Most participant direction programs, however, did not offer a worker registry to assist participants (Griffin, 2005).

**Advice/counseling.** Advice/counseling was often considered essential to the successful direction of the participant’s supports and services (Bradshaw et al., 2006). A designated professional, such as a “support broker” (Massachusetts Department of Mental Retardation, 2007, p. 4), “service facilitator” (Caldwell, 2007, p. 551), or “peer specialist” (Revel & Inge, 2007, p. 126), provided advice/counseling on things such as benefits, plan development, and individualized budget creation.

**Managerial assistance.** Managerial assistance focused on supporting participants as they engaged in employer responsibilities. Professionals (Bates, 2006) or peers provided this support (i.e., other participants experienced with directing their supports and services; Claypool & O’Malley, 2008). Participants could receive support with employing activities like scheduling,

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recruiting, and supervising providers, creating a backup system, and interacting with the financial management service agency.

**Information dissemination products.** Information dissemination products were “materials that [were] widely distributed and posted on state and agency websites” to assist participants in understanding participant direction (Massachusetts Department of Mental Retardation, 2007, p. 23). These products included items such as PowerPoint presentations (DHHS of NC, 2005), handbooks or manuals (Bradshaw et al., 2006; Minnesota Department of Human Services, 2004), or resource binders “containing educational materials” (Masters, 2006, p. 586). The purpose of these products was “to support informed decision making about services, delivery approaches, and strategies for navigating systems” (Kendrick et al., 2006, p. 10).

**Service quality monitoring.** Service quality monitoring was most often addressed in reference to Medicaid-funded programs in which “the state Medicaid agency maintain[ed] responsibility for monitoring service delivery” (Tritz, 2005, p. CRS-11). Some programs allowed the participant to “monitor the quality of the services received,” while other programs required a professional to remain “‘at the helm’ for quality assurance” (Infeld, 2005, p. 10).

**Service coordination.** Service coordination was often provided in tandem with other aid and assistance structures such as advice/counseling and managerial assistance. Service coordination consisted of “disability care management” (Surpin, 2007, p. 58) and the coordination of personal and medical care needs. Professionals providing service coordination assisted participants “to identify resources to achieve [the] goals” (Cloutier et al., 2006, p. 5) identified in the care plan (DHHS of NC, 2005). In some programs, service coordination was required while, in others, a professional assisted only “when requested” (Masters, 2006, p. 384).

**Participant training.** Participant training typically included training to assist the participant with the “roles and responsibilities” of “recruiting, hiring, and supervising their

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personal assistants” (Surpin, 2007, p. 58). Other topics included “personal advocacy and self-management” (Fleming-Castaldy, 2008, p. 17) and “seeking emergency support through local organizations” (McGaffigan, 2008, p. 12). In some programs, training was a choice; however, others required successful completion of training on the “fiscal and legal responsibilities of employment” (Griffin, 2005, p. 14) prior to participant directing (Doty, 2004).

**Provider training.** Provider training typically included common trainings, such as CPR certification, first aid, and nursing care delivery (McGaffigan, 2008). This training was not specific to the individual; rather providers were required to “undergo the same training as traditional agency workers” (O’Keeffe et al., 2005, p. 39)

## Discussion

This research analyzed the design of participant direction programs in long-term care to determine the structures in place to facilitate implementation of the programs and to support program participants. We accomplished this through a qualitative document analysis of 53 peer-reviewed documents and gray literature documents. We identified two components, policy and aid and assistance, into which we categorized 14 structures—three in policy and 11 in aid and assistance. We defined the structures of each component by a continuum of participant-directedness—the degree of choice and control over that structure.

There were three *policy* structures identified regarding the opportunity for participants to direct their supports and services. Within each structure, programs had differing strategies that fell across a wide continuum. The first structure, option to participant direct, was on a continuum from limited options in some states (e.g., being available only in certain geographical regions of a state) to being the default option in another state. The second policy structure focused on two provisos for participation. The first related to the individual’s capacity to participant direct. At one end of the continuum, some programs permitted anyone who expressed an interest,

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regardless of intensity of support needs, to participate while at the other end of the continuum individuals were required to pass a training course or test evaluating the individual's capacity. Closely related to the issue of capacity was the structure addressing surrogate decision-makers. Again, the continuum extended from broad participation regardless of support need where the individual may have a surrogate to assist in all decision-making to the other end of the continuum where an individual had to be fully capable of directing all aspects of his or her supports and services. Other parameters for participation included characteristics of the individual or provider that prohibited their participation. The third structure concerned provider qualifications, which included three continua addressing background check requirements, permission to hire family or friends, and license requirements for providers. Background checks were either required or at the participant's discretion, though encouraged. Hiring of family and friends ranged from prohibiting hiring of any relatives to no restrictions on who may be hired. The last continuum, licensing requirements, were governed by the funding source.

The policy structures identified all focused on how participant direction programs are implemented. The structures identified three areas of debate within the field:

- Who is capable of participant directing?
- Should supported, surrogate decision-making be permitted?
- Who is qualified and eligible to provide paid services?

Findings indicated that there is still substantial debate around these issues, and policies range from extremely restricted to extremely flexible, despite research showing that people with significant support needs participate in and benefit from supported decision-making in directing their supports and services (Gross et al., 2012; Neely-Barnes, Graff, Marcenko, & Weber, 2008) and hiring family and friends to provide long-term care (Whitlatch & Feinberg, 2006).

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The second component, *aid and assistance*, had 11 structures: (a) financial management services, (b) employer of record, (c) emergency back-up, (d) worker registry, (e) advice/counseling, (f) managerial assistance, (g) information dissemination products, (h) service quality monitoring, (i) service coordination, (j) participant training, and (k) provider training. These structures represented the various types of support provided by the state or its agent to program participants. The continua associated with each of these structures concerned whether or not the structure was available to anyone choosing participant direction and whether or not its use by the participant was required.

The component of aid and assistance encompassed various types of support. Availability of and requirements to use these supports depended on the design of the program. The most frequently available and required structure was financial management services, which was commonly paired with the structure of employer of record. These two structures, while supportive of participant choice due to their frequent availability, are also limiting of participant control when they are required to be used. We believe that participant direction programs designed to be restrictive of participant control over financial and legal aspects of employment is reflective of the fact that it is easier to hold an agency or organization accountable for funds than it is to hold an individual accountable. There is a common misconception that lack of organizational oversight (i.e., agency accountability) will result in participants taking advantage of the system and using monies unwisely; however, research has not supported that misconception. Participants directing long-term care supports and services have demonstrated an ability to be good managers of their funding streams (Caldwell, 2007), typically obtaining more services hours than are possible under agency direction of those same dollars (Matthias & Benjamin, 2008), often because they choose to employ family and friends to provide services.

### **Implications**

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The findings of this study have several implications for the field of participant direction, specifically regarding policy around program design and rigorous research. This research analyzed how programs of participant direction are designed and focused on the programs' structures in several contexts. First, participant direction represents an ideological desideratum, namely, the autonomy of persons in long-term care. The core concept of disability policy entitled "autonomy" (Turnbull, Beegle, & Stowe, 2001) reflects the programmatic value of "choice," the constitutional value of "liberty," and the legal value of "consent." If these values are to mean anything for individuals in long-term care, it will be because the structures of long-term care programs advance them. It is important then, to understand that these structures play an instrumental role in treating persons in long-term care as equally possessing those values of persons who do not have disabilities and are not in long-term care. Therefore, considering the social model of disability (Turnbull & Stowe, 2001), a person is only incapable when we fail to create a supportive environment. The structures under aid and assistance are designed to support participants in participant direction. The inclusion of these structures in the design of programs, while still allowing for participant control, creates the supportive environment necessary for persons with any disability to engage in participant direction to the degree that they desire.

Second, this research on the structures that shape participant direction responds to the inability to use previous research to justify or design effective long-term care policy. In existing research, definitions of predictors and outcomes are elusive; vague explanations of variables are abundant; and study designs do not allow credible generalization (National Council on Disability, 2004). These shortcomings matter because long-term care involves a good deal more than policy debates about eligibility, costs, and outcomes. It is important to know who qualifies and why, and what their costs and outcomes will be if in long-term care. If we have a clear understanding of the structures that operationalize long-term care, then we can better understand



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the implications (costs and outcomes for participants) of various means of providing long-term care (agency direction, participant direction). This study provides insight into the structures of participant direction (see Table 1), a first step in developing a clear taxonomy.

Third, understanding the structures does more than assist policy leaders and advocates to design supportive participant direction programs, it also permits research to have a common ground – a common understanding – in which to investigate structures and outcomes. Little can be done to shape federal or state long-term care policies if the structures of long-term care are not comprehensively analyzed and understood. If research is indeed in service to policy and practice, and if policy and practice are indeed in service to legal, constitutional, and ethical treatment of individuals in long-term care, then we must have a common understanding of the structures (policy and aid and assistance) that guide implementation and support participants.

Fourth, structures of long-term care are financed through two major entitlement programs, Medicare and Medicaid. Each is implicated in the current debates about entitlements, federal fiscal health, and the social contract. If there is to be restructuring of either of those programs, then restructuring of participant-direction seems inevitable, and research about the structures themselves seems necessary to inform public discourse and decision-making.

### **Conclusion**

We used grounded theory methods to identify the design elements of participant direction programs in long-term care. This research creates a foundation for common understanding (a taxonomy), allowing standardization, and, with it, application of outcomes research that can investigate whether the programs advance or inhibit the values that our national policy declares. Future researchers and policymakers should consider the findings of this research as they investigate and make decisions about the future of participant direction programs.

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Table 1

### *Components and Structures in Programs of Participant Direction*

<b>Components</b>	<b>Structures</b>	<b>Definitions</b>
Policy	Option to participant-direct	Election of or choice of the consumer or surrogate to direct the consumer's supports and services
	Participation stipulations	Requirements or limitations regarding participation in programs of participant direction by the consumer or surrogate decision maker
	Provider qualifications	Regulations or practices regarding who may be hired to provide the services outlined in the individualized budget
Aid and Assistance	Financial management services	Assistance with or responsibility for all payroll management (e.g., paychecks, taxes, withholdings) and goods purchasing relative to the plan of care, commonly referred to as a fiscal agent or intermediary
	Emergency back-up	Maintenance of or assistance with the development of a back-up system or plan for when scheduled workers are not available
	Worker registry	Maintenance of or assistance with the development of a registry that lists available and qualified service providers
	Advice/counseling	Assistance provided in the form of advice and counseling regarding things like service options, personal goals, identifying training needs, etc.
	Managerial assistance	Assistance with employer responsibilities related to service providers as described in the <i>what</i> category
	Information dissemination products	Paper, audio, video, web-based products or activities designed with the intent of providing needed information to consumers, surrogates, or service providers regarding participant direction
	Employer of record	Role of legal employer of the service providers
	Service quality monitoring	Assistance with the responsibility of assuring that the services received by the consumer are

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	quality services that meet the consumer's needs
Service coordination	Assistance with the responsibility of identifying and accessing appropriate and needed services and resources in the community
Participant training	Training of consumers or surrogates on the activities associated with participant direction of the consumer's supports and services
Service provider training	Training of service providers that is not consumer specific, such as CPR certification, first aid, and generic care delivery (e.g., transferring, lifting, bathing), and workplace behaviors

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